Les opportunités et les contraintes liées à la recherche sur le terrain de technologies d'assistance dans les zones mal desservies

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Abstract

The particular needs of disabled children in the 'Majority World' is under researched. There is an assumption that children's needs are the same as those supported by well-developed healthcare infrastructures. Field research is necessary to understand the design challenges, opportunities and affordances for these children. For research and design to meet their unique needs, processes must start with children in their own communities.. In order to ascertain design requirements of AAC devices and applications for such communities, we took our prototype AAC device into the field as both a tool 'in development' and as a communication artifact to enable us to understand the needs of these children. The project PI (an Autistic self-advocate) situates research practice within the 'nothing about us without us' paradigm, accordingly, project goals are to work with children to create communication tools to help them express their goals, interests and needs and enable the co-creation of new tools with them.

Keywords: self-advocacy; Indigenous communities; user-initiated design; non-medical model

Introduction

Little is known about the particular needs of disabled children 1 in the Majority World 2 (Balaram, 2001), and there is an assumption that their needs are largely those of disabled children in countries with well-developed healthcare infrastructures. G3ICT (2013) note that there are an estimated 120 million disabled children in «developing countries» with little access to medical or institutional supports. Alper & Groggin (2017) highlight that access to digital and communication technologies need to be considered along with other technological supports in order for disabled children to gain literacies and participate socially, and that barriers to «inclusion may be compounded by intersections with class, caste, race, ethnicity, gender, sexuality, culture, religion, and geography» (p. 727). Field research helps us understand design challenges, opportunities and affordances for Majority World children, both where they live and play. Even if it were possible, lab-based user studies are unlikely to capture the particularities of these children's use of technologies intended to help them communicate and interact in their daily lives. Moreover, children rarely respond in artificial settings as they would in their

natural environment, engaged in routines and with people familiar to them. In situ research is therefore necessary to ensure that designs initiated by the real needs of individual children, as well as stakeholders such as parents, educators and caregivers, are understood as emerging from the child's lived experience, highlighting challenges and barriers to inclusion particular to their lives.

Our project, Diseñando para el Futuro (Designing for the Future), is intended to build design capacity in the creation of custom devices and adaptations for disabled Indigenous children in underserviced areas in Cochabamba, Bolivia. This capacity building changes the context in which a child functions, helping the child better engage with the world around her and discover greater autonomy. We argue that the design of assistive technologies must be initiated with the child's direct involvement as much as possible, and endeavor to conduct field research at every stage; the researchers' role is to support and guide, filling in missing skills and experience. Our goal is more than designing for disability; we seek to ensure that people have the proper tools and knowledge to build their own custom solutions for themselves as well as to create a local network that nurtures people's skill and helps them help others.

We contribute to the body of research in applied Disability Studies and the design of assistive technologies by presenting our experience of implementing our approach to disability design in practice. Our design tactic combines a multidisciplinary design team, field research and iterative prototyping with, for and by children, parents, educators and caregivers who will use assistive technologies in marginalized contexts. Results from our project show that focusing on nurturing self-advocacy through design favors the development of design thinking that starts with the needs of the individual.

Existing Design Methodologies

Our approach initiates the design process with the goals, interests and needs of the individual (Cole & Nolan, 2019) who will use a device, resonating with Ladner's notion of «design for user empowerment» (Ladner, 2015, p. 24). The goal is to reframe disabled individuals—users of disability technologies—as «valuable knowers and experts» and to «foreground the political, cultural, and social value of disability embodiments» (Hamraie, 2016, p. 20). We aim to engage disabled people as well as other stakeholders such as educators, parents or caregivers, at every stage of the design process, starting from understanding their needs in their real-world context. In this sense we look to feminist technoscience scholars (see Mauldin, 2017) to not just challenge the use of technoscientific artifacts, but to challenge the notions of who conceptualizes, designs and creates technoscientific artifacts; in this case Indigenous children, their families and caregivers who have little or no access to the supports provided by Western medical models. Our approach, therefore, has the goal of designing with and by disabled people: as researchers we play the role of facilitators, supporting individuals to define requirements, design, develop and test prototypes of their own solutions according to their changing needs. When working with disabled communities, classical user-centered design (Norman & Draper, 1986) and participatory design (Schuler & Namioka, 1993) approaches fall short where promoting self-advocacy and building capacity is of equal or greater importance than informing product development. Ladner (2015) pointed out that classical design approaches need to be rethought in order to develop greater awareness of user experiences, contexts and meaningful outcomes for disabled users. While both user-centered design and participatory design are human-centered approaches—in the sense that they follow a life-cycle of analysis, design, development and testing that aims at gaining a growing understanding of who will be using a product— they need to be

extended when they target the disabled community since «typical designers and developers are not disabled» (Ladner, 2015, p. 27). User-centered design, for instance, involves the users only for usability testing and does not offer tailored solutions for specific individuals (Norman, 2005). Participatory design focuses on designing and testing with users. Users are considered as design partners and their feedback and insights are «used» to design and develop a product, being the original design team in control of the design process at all the phases. With the disabled community, we aim at engaging people to be «active producers and innovators» (Heeks 2008, p. 33) and learn from the process so that they could apply the new skills to solve emerging issues. Enabling individuals to express their own needs in increasing levels of complexity and confidence is foundational for nurturing autonomy and self-advocacy (Nolan, Raynes-Goldie & McBride, 2011); seeing every individual as both unique and uniquely positioned to challenge universal design's top down and post-disability rhetorics (Hamraie, 2017; Thumlert & Nolan, 2019). We aim to extend and enhance user-centered and participatory design to provide people with the means and expertise to deal with local conditions and individual needs. Closer to our vision, experiences from participatory design field research for designing prosthetic legs in Cambodia (Hussain et al., 2012) led the authors to propose an alternative framework for participatory design with marginalized communities that focuses on building a nuanced understanding of contextual, social and cultural factors as well as instructing people on design methods and prototyping.

Our project embraces the Do-It-Yourself philosophy with the goal of enabling people to design, build and share their personalized solutions (Hunsinger & Schrock, 2016; Kuznetsov & Paulos, 2010) and therefore support self-determination (Ladner, 2015), and increase the technical expertise of disabled people through the design and development of the technology that is intended for them. Do-It-Yourself refers to any act of creation or modification that does not engage a professional (Kuznetsov & Paulos, 2010) and fosters the creation of communities (physical or online) of «expert amateurs» that collaboratively work towards building, reconfiguring or modifying artifacts (a piece of software, physical objects, interactive devices, etc.). Flexible Do-It-Yourself practices have the potential to create individualized and easier to procure assistive technologies. Mainstream technology often marginalizes people with complex needs who require ad-hoc customizations to access mass-produced assistive devices (Lundälv et al., 2014); multi-touch input, for instance, requires fine motor skills and is nonfunctional for individuals with motor impairments (McNaughton & Light, 2013). The main challenge of implementing Do-It-Yourself for disability design relates to a lack of confidence in participant's own practical and technical skills (Hurst & Kane, 2013). This is mitigated through online (Buehler et al., 2015) and local community makerspaces (Hook et al., 2014), providing access to infrastructure and guidance that increase expertise. Access to tools and assistance allows non-professional designers to both fabricate difficult-to-find parts for broken devices (Hurst & Kane, 2013) and increase the practicality and robustness of assistive technologies (Hook et al., 2014).

Disability Self-Advocacy Literature

The focus of Nolan's applied work over the past decade has been in the construction of custom adaptations for children with disabilities (CBC Arts, 2016; Henderson, 2011), starting with a period of collaboration with the Adaptive Design Association in New York (Jones, 2014) and culminating in supporting the establishment of the NGO Diseñando para el Futuro in Bolivia, which is controlled and run by Bolivians who work with organizations supporting Indigenous disabled children in Cochabamba. As an autistic adult and a

member of the autistic self-advocacy movement and proponent of the social model of disability, his work has focused on an approach to design that is initiated with the goals, interests and needs of the disabled individual, extending to modify the external environment to meet those goals, interests and needs (Nolan & McBride, 2015). Disability advocates and many disabled adults subscribe not only to the social model of disability, but to 'identity first language' versus 'person first language' (Gernsbacher, 2017). A search of the Internet for the terms 'identity first language' and 'person first language' shows a wide debate on the issue, and this debate continues on into academic journals (Dunn & Andrews, 2015; Peers, Spencer-Cavaliere & Eales, 2014). It appears that disabled adults tend to be more on the side of 'identity first' language (Cole & Nolan, 2019; Gernsbacher, 2017). For some individuals disabilities are defining points of identity, and we often hear disabled adults referring to themselves as autistic person, deaf person, blind person, rather than person with autism, person with deafness, person with blindness. This identity first, social model of disability perspective positions the individual as being disabled by social norms and social infrastructure that disables them more than physical or cognitive impairments. As well as seeing the individual as having been disabled by societal structures that are not inclusive and equitable, it is equally important to focus on the disability as a defining barrier to inclusion for an individual.

Disabled people struggle daily to modify the world around them to meet their needs; they must hack to live (Cole & Nolan, 2019). This has led to the central tenet of critical disability studies and disability advocacy: «nothing about us without us» (Werner, 1998). Self-advocacy is a rights movement for people disabled by societal institutions and built environments that are not designed or structured to meet the needs of the disabled to the level that they meet the needs of others. It is a complex topic with a variety of perspectives that vary across fields of inquiry, cultural contexts, and the needs and aspirations of individuals and groups (Goodley, 2010). From childhood and throughout their lives, disabled people's lives are organized around the needs of others, and lack opportunities to develop their own sense of autonomy and assert that autonomy in a meaningful manner. Pierce and Allen (1975) argue that the lack of autonomy and self-direction is the fundamental form of discrimination and oppression that starts in childhood. They termed this form of discrimination 'childism' and asserted that this organization of a child's life to meet the needs of others is the foundation of all forms of oppression and discrimination. Disabled children and adults are often infantalized by medical-model social institutions that do not support or actively restrict the development of autonomy and self-advocacy. All children require opportunities to explore and express individuality and autonomy (Horn & Kang, 2012; Nolan, Raynes-Goldie & McBride, 2011), particularly when they have multiple disabilities and are unable to express themselves verbally or move independently. The challenge of designing with/for children is to use integrated teaming where professionals and family members work in concert to ascertain the child's interests and needs in order to enact self-determination on the child's behalf and, to the greatest extent possible, enable children to do things for themselves (Horn & Kang, 2012).

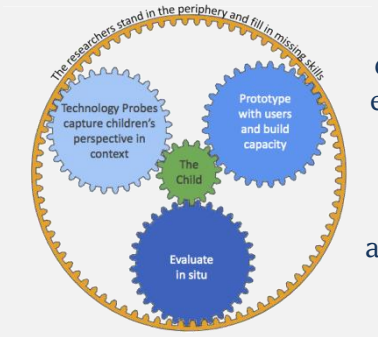

Figure 1. A visual representation of our design approach.

Each phase is initiated by the child and her needs: technology probes are used to understand and reveal

children's needs from their own unique perspective. Prototypes that materialize the design ideas originating from the children are built together with the users and evaluated in situ. The role of the researchers is to support and guide, filling in missing skills and experience.

Figure one is a picture of a large cogwheel with four cogwheels inside intended to give the impression that all the wheels each move the other as they turn. The small cog in the center has «The Child» written on it. The three cogs surrounding it say «Technology Probes capture the children's perspective in context», «Prototype with users and build capacity», and «Evaluate in situ». The largest cog that encloses these four says «The researchers stand in the periphery and fill in missing skills.»

Since 2009, we have been exploring various assistive devices in our lab as research/fabrication exercises, to support a nonverbal child with limited mobility in our child care center, in the form of custom keyboards, soft keys and wearable electronics with recorded speech (Henderson, 2011). The goal was to develop tools to help the child communicate her goals, interests and needs. The project ended when the child moved to another early learning setting, but the work provided the foundation for our low-cost hackable approach to assistive technologies. Central to our approach is to initiate the design process with the individual as early as possible and to tailor development to the needs of a specific individual. The RE/Lab (previously known as the EDGE Lab) was founded by one of the authors of this paper, who is an autistic researcher/designer, in order to explore this emergent approach to design; the project in Bolivia was intended to focus on autism related communication and mobility issues. However, the needs, goals and interests of the individuals we met in Cochabamba took precedence over our original plans (Ladner, 2015).

For marginalized communities, where assistive technologies cannot adapt to the specific users' needs (Heeks, 2008; Hussain et al., 2012), we focus on self-advocacy by enabling communities to build the tools themselves and learn design thinking. We have revised the classical human-centered «analysis, design, prototype and test» approach to promote children and stakeholders' active participation at each step of the design process. The overarching idea is that researchers learn adaptive design needs from field experience and conceptualize solutions with the stakeholders, and work with local communities to create devices and adaptations while teaching them how to create their own solutions. Figure 1 shows a graphical representation of our iterative design process.

Analysis And Design

We combine observation, focus groups and interviews, with the deployment of technology probes (Hutchinson et al., 2003): «tool[s] to think with» (Papert, 1981) aiming to better understand children's interest, goals and needs from their own perspective. Technology probes are intended to work in real-world settings and have simple functionality that allow children, their families, caregivers and educators to generate design ideas by interacting with the technology. The technology introduces new design possibilities and capture children's perspective in their daily context. They are not demonstration nor functional prototype, instead they are open-ended seed technologies that facilitate meaningful conversation between the team and the stakeholders and allow people to envision emerging designs.

Researchers have «much to learn about children and children's experiences from the children» (Dockett & Perry 2007, p. 48) and we advocate initiating design with children's input as early as possible. Typically, researchers investigating issues related to disabled children rely on adult interpretations of children's experiences. As a result, children's perspectives on matters that affect their lives are excluded. Children have a right to

participation and to express their views about issues that affect their lives. Article 12 of the Convention on the Rights of the Child (CRC) recognizes «the potential of children to enrich decision-making processes, to share perspectives and to participate as citizens and actors of change» (United Nations Treaty Collections, 2016). The CRC is central to our engaging children as active participants and to observe them in their natural community-based surroundings, where they feel most comfortable, rather than in a lab setting (Caplan, Loomis & Di Santo, 2016).

Prototyping and Testing

We see prototyping as an interactive process where users are supported in building artifacts and determining design efficacy. To this end, we have established a fabrication lab in Cochabamba: a makerspace where people can come together and can engage in fabrication workshops (Hook et al., 2014). Our lab is a step in developing a social network that would connect disabled children, their parents and caregivers to build accessible solutions using local expertise, resources and materials, through which we can develop a nuanced understanding of Do-It-Yourself approaches and the design of assistive technologies in underserviced areas.

In our process, we generate the prototypes with the users that are the results of their interactions with the technology probes. At the same time, we seek to build capacity by teaching them how to build or modify the technology by themselves. We start with the children who are supported in articulating their needs/goals, caregivers who have an intimate knowledge of the child, educators, administrators and therapists who can advocate on the child's behalf, and our lab staff who are able to manage and engage people in design/fabrication process. Our staff are responsible for standing at the periphery; we as researchers are ready to help build capacity wherever needed, observe the process, and refine our methods. In fact, we are prototyping the design of design teams, developing structures for ensuring that everyone can do the most for themselves within a context of a design team with shared goals focused on the needs of the child. We are fostering a radically individualized design strategy, in opposition to a Universal Design (Balaram, 2001) that is not tailored to the individual and cannot address complex and changing needs.

As a last step in the design cycle, we evaluate the prototypes in situ with the stakeholders to ensure that our designs addressed the original needs reveled by the probes and to observe how the introduction of a new technology changes the way children interact with their environment.

Method and Procedure

Research reported on in this paper was conducted in and around Cochabamba (October 2015, May 2016 and October, 2016). Our unique transdisciplinary experience brought together divergent yet commensurable skills and experiences. The first author's computer science background, with experience in physical computing and interaction design was complemented by his fluency in Spanish. He contributed to hardware development and field testing. The second author, and project lead, contributed his lived experience as an autistic adult, directing 'user-initiated design' fabrication research initiatives (Le, 2016), project logistics, and fabrication learning activities. Author three's expertise in international development work with children, families, and educators provided the foundation for community engagement, interviewing and data collection.

We currently have eight sites participating. During the first visit, the team visited five sites supporting over 200 children (two schools for children and three orphanages for disabled children), and adults assisting them. An equine therapy center and two additional

schools joined the project during our second and third visits. The schools service children 4-8-years-old with mild to profound disabilities, including visual impairments. Orphanages host children according to their age range, from infants to young adults. Young children of families with fewer economic resources also reside in the orphanages on a short-term basis. During the first two visits, we interviewed two parents, ten educators and caregivers and one administrator. We also interviewed and ultimately hired two local individuals with extensive experience in the disability community to manage our fabrication lab. They helped us maintain ongoing connections with the research sites, as well as conduct fabrication workshops. We maintain regular communication with them using Skype and WhatsApp.

After the first visit, we were able to identify a number of potential projects to prototype, including: Augmentative and Alternative Communication (AAC) devices, modified footrests for wheelchairs, children's back supports, walking canes, ramps, and learning materials. Stakeholder interviews led directly to the development of our first technology probe to explore different input modalities. We developed the AAC Comunicación Aumentada Móvil (Mobile Augmented Communication) probe, designed to enable nonverbal children to express themselves with minimal adult intervention by using different touch modalities for text-entry. During our field visit to the young children's orphanage, it was determined that a text-entry communication device would not be appropriate for their use because of their profound disabilities. However, the device could benefit the children living in the youth/adult orphanage. For example, Diego 3 is nonverbal and the caregivers find it challenging to understand his needs. The goal for Diego is to teach him how to use the device to express his needs to others. Educators working at a school for children with disabilities stated their interest in our prototype. They shared that many of the children are nonverbal or have limited expressive communication skills, but have sufficient cognitive and motor skills to use the AAC device as a medium for expressing themselves. This was realized when we tested the device with several of the children. Children enrolled in a therapeutic horseback riding program also participated in field testing the device. With their parents present as observers, several children had the opportunity to engage with the device with sustained interest and curiosity. Sofia, (16-years-old) and Mateo (15-years-old) were interviewed about their experience using the probe. Both children have limited expressive communication and low literacy level.

Six workshops (16 educators and 12 parents) were conducted at the fabrication lab between visits, which allowed our team to interact with educators and parents, helping them create adaptations such as finger separators, balance boards, rocking seating, soccer balls with sound for visually challenged children, and stirrups for horseback riding. During these workshops, participants learned our approach to design thinking, and we learned about the needs of the children, the kinds of objects they needed, and we checked in with the participants to review the accuracy of the data collected in more formal interactions. We are presently only working with adults (Figure 2), some who are disabled. In the six workshops so far, we have fabricated physical adaptations and we are now moving towards building low-cost, electronic-incorporated objects.

To access our sites, we obtained consent from Cochabamba region social services, and written consent from the directors, staff and volunteers working at the orphanages. We next met with staff and volunteers to explain the project and address potential questions/concerns. We developed a mechanism for consent that respected each person's literacy skills, asking if they preferred oral or written consent. All participants chose to

provide oral consent. To ensure voluntary participation, people were informed that they could withdraw from the study at any time without consequences. If participants decided to withdraw, they could also choose to not have their data included in the study.

Interviews and data collection were organized around the availability of children, parents, educators, and therapists. In-person interviews provided data related to children and stakeholders' needs (see Participant Data). One focus group was also conducted at one of the orphanages in preparation for a workshop. After the workshop, we interviewed participants to gather more detailed information that arose from the focus group. Photographs were used as a data gathering tool for the researchers to document the learning process of individuals and groups to design and build custom objects as well as a way for participants to document their own progression through the project.

Including children in the project required parent/legal guardian consent and children also provided assent prior to participating in any research related activity. For the two children who participated in the interviews, consent was provided by the director of the school who had legal guardianship of the children. An interpreter who was familiar with the program worked with one of the researchers to inform the children about the activity in child appropriate language. The children were informed that they could stop the activity at any time. We also observed children closely for signs of not wanting to participate (e.g., non-verbal body language), and unless we could confirm a child's interest, we defaulted to the assumption that the child did not want to continue participation.

Participant Data

At present, 98% of the participants and families in Bolivia identify as Indigenous, the other 2% identify as mixed. At the various centers we are working in, 50% of the staff speak one of Bolivia's Indigenous languages. Over all, we are directly engaged with over 230 children, as well as 30 staff members who are indirectly impacted. Our workshops have brought 14 center staff and two parents into our space to learn techniques, and our lab director has identified 67 other individuals we have been in contact with. As well, we have been asked by the director of Cochabamba's Servicio Departamental de Gestión Social (SEDEGES) who is responsible for disability programs, to extend our work across the city of Cochabamba. This is presently beyond our capacity, however, it reflects support for our initiative at the local government level.

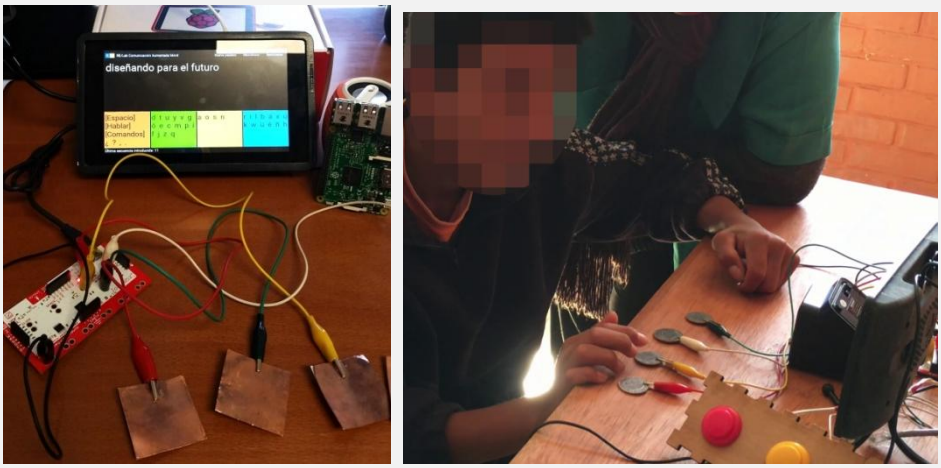

Figure 3. Deployment of the AAC technology probe.

The two images in figure three show our alternative and augmented communication device being field tested in Bolivia. The first image has a makeymakey touch interface hooked up to 4 copper squares. The second image shows a non-verbal Bolivian child using a different version of the input device hooked up to 4 round coins.

The AAC Toolbox

The AAC probe was developed as a toolbox for exploring different input modalities for allowing nonverbal children to input text and produce meaningful utterances (Figure 3). The main features include using H4 Huffman Codes (MacKenzie, Soukoreff & Helga, 2011), onscreen and physical text input mechanisms, open-source hardware, and multi-lingual functionality that embraces communication in local dialects and accents. Four input points (switches, buttons, soft circuits or toggles) can be placed anywhere a child can trigger them, enabling text entry. We used the Raspberry Pi 3 low-cost, open-source, single-board computer to which we attached (in a custom 3D printed enclosure) a multi-touch display, four physical buttons, a MakeyMakey input device (Collective & Shaw, 2012), a microphone, and speakers. Children can directly touch the on-screen keys or physical buttons to enter characters and compose sentences. Alligator clips from the MakeyMakey connect objects such as coins or play-doh compound, turning them into input keys; this provides open-ended affordances for text entry, thus offering insights on desirable physical input. Special commands are provided to delete last character/whole sentence, move backward and forward within sentences already introduced and «play» a sentence. The system provides different audio feedback for successful key pressed and character typed, to help children with visual impairment. The device records words using the voice of a parent, educator or caregiver, with the intention to ensure that our device speaks words in the languages, tones, dialects, slangs, idiomatic phrases that the child hears around her.

In developing the technology probe, we chose a low-tech approach to speech generation by recording human voices. In terms of the multilingual functionality, we abandoned the idea of computer speech synthesis, due to the cost and inflexibility. Speech synthesis such as SpeakJet (https://sparkfun.com/products/9578) or textspeak (http://textspeak.com) are still rudimentary and limited for our purposes, and the kind of systems available in, for example, Apple and Android devices, are tied with technology that exceeds our price point and design goals. The rationale for eschewing speech synthesis, in favor of human generated speech is manifold, and largely situated in perspectives from critical disability studies that highlight the need for autonomy and self-advocacy (Nolan, Raynes-Goldie & McBride, 2011). Available commercial tools for speech synthesis offer predefined set of mostly English voices, or at best, standardized and depersonalized voices that have little connection to the kinds of speech sounds people hear in their daily lives. Our technology probe, instead, provides a functionality to record words using the voice of a parent, friends, siblings, teachers or caregivers at the orphanage. This way the system would allow the child to speak with the voice of someone familiar to her. New words can be pre-recorded (creating a custom vocabulary) as well as added any time the system recognizes that a word is not in the vocabulary. The intention is to ensure that our device speaks words in the languages, tones, dialects, slangs, idiomatic phrases that the child hears around her.

We chose orthographic as opposed to other types of symbol sets (e.g., icons or pictograms) for a few reasons. Based on interviews with parents and educators during the first visit, we learned about the kinds of educational opportunities and interventions undertaken in the schools. We observed that these particular nonverbal children were

gaining a facility with written language, in this case Spanish, and educators indicated that they wanted tools that support their direction of language development. At the same time, we were curious about how we could build on our prior research experience in providing children with tools to communicate outside of immediate family and caregivers, to express their own needs in an open-ended manner (Gaston, 2011). We hypothesize that being able to provide children with technologies that would help them communicate real words that are already familiar to them would play an important role in helping them establish a sense of self and identity as a social individual, and it may encourage greater self-efficacy than using a preset suite of close-ended images.

Emerging designs

Our interviews with educators, therapists and caregivers following the in situdeployment of the AAC device led to the discovery of unexpected unmet needs, as we had hoped. That is, the technology probe met with our expectations that through engaging children, educators, therapists and caregivers with the technology we aim to develop for them, we have been able to unveil design opportunities that would not have been possible to elicit otherwise. A variety of design challenges were identified. Some of them emerged from possible evolutions of the probe into applications that exploit analogous input/output mechanisms. For instance, in addition to the use of the device as a support for communication, physical input could be helpful to develop engaging and playful embodied interactions to improve patterning, sequencing, seriating and spatial skills. At one of the schools for children with special needs, educators were already using icons and pictograms to build identification between real world objects and words. While observing Mateo interacting with the device, one educator envisioned using it to strengthen children's cognitive skills, for instance for matching physical objects or colors with the on-screen pictures or shapes. Additionally, caregivers at the orphanages expressed the need to create visual interactive communication boards customized to individual children's needs, by including pictures of personas, objects, and scenes from their daily life. Other design challenges emanated by the fact that our exploration created an environment where people felt comfortable in engaging with an open technology and jump into the conversation providing new design ideas. We discovered a wide range of customization needs for the site we have visited, such as the need for a newly designed bathing chair that was more amenable to local construction methods, as well as various standing and balancing modification for the children's therapy spaces, and sensory interactive experiences that could be constructed out of local materials. Some of the unique designs we are developing are stirrups that will enable children with limited leg strength to engage in equine therapy activities (Figure 4), and a wooden interactive pre-braille toy that enables blind children to learn the shape, orientation and spatial configuration of braille elements (Figure 5). Using the technology probe in-the-wild, therefore, supported meaningful discussions with users and disclosed potential of using unfinished prototypes as a hermeneutical approach for eliciting new designs and customizations in marginalized contexts.

Although Sofia provided minimal feedback on her experience, her comments are valuable for next steps. Sofia shared that she found the device easy to use and «liked everything about it.» She said, «writing my name was easy.» When asked how we could make the device better, she said she wanted stronger speakers in the next version. She also preferred using the touch screen rather than the buttons. In contrast, Mateo preferred using physical inputs (Figure 2) to the touch screen, saying that he likes physical objects because they are «graspable». This supports the need to provide multiple input choices to

ensure access to marginalized groups of people that would be otherwise excluded from mainstream development on touch-based devices.

From the perspective of designing assistive technology for children with disabilities, multi-touch showed to be the preferred input modality for children with fine motor skills (possibly due to the direct selection of the character on the screen). Others, with more limited body movements, preferred physical input, such as the physical buttons, due to the physical feedback and the fact they were easier to select and push. However, this modality required additional adult guidance for the children, who found it challenging at the beginning to match the physical input with the position of the on-screen key they desired to type. This finding supports the need to provide multiple input choices to ensure access to marginalized groups of people that would be otherwise excluded from mainstream development on touch-based devices (McNaughton & Light, 2013). Our experience in the field also confirmed the need to design assistive technologies for robustness (Hook et al., 2014). For instance, our 3D printed enclosure for the probe was well designed to attach to a wheelchair, but the enclosure was too delicate and unbalanced for rough use. We learned that communication devices need to be self-stabilizing, with customized easy grip and hold affordances, as well as robust enough to survive the rigors of use by children who may 'throw' it due to muscle spasms or emotional distress. Children who tested our device showed curiosity and enthusiasm; they were able to communicate with relative ease. However, the excitement and distraction of visitors in the classroom made sustained exploration difficult. As well, despite precautions, the relative fragility of the device made leaving it in the classroom impossible. Still, the direct experience with the children has enabled us to revise the design significantly, and the next version will be constructed mostly with locally sourced materials.

Towards Disability Design For Underserviced Communities

By offering assistive technologies and customized designs based on the children's individual needs, we help stakeholders support children's right to freedom of expression. We suggest that the design of assistive technologies should be left open and should be localized by the user (children, parents, educators, etc.) to achieve high repurposability. This represents a significant design challenge with respect to the trade-offs between tailorability/configurability and the demands of non-technical users. Designing for open-ended affordances and custom adaptations rely on user creativity and input; however, when the end user of an object is a child, researchers often turn to key stakeholders in the child's life for input on how children engage with their world. Stakeholders' observations of children are key to understanding children's social environment and how they construct meaning of objects and experiences in their environments. However, it is paramount to directly engage children in their natural settings as they interact with technology. Gathering data from «realistic settings and situations that reflect children's actual performance» (NAEYC, 2003) will document their activities in the context of their daily routine. Our endeavor to build capacity for local fabrication showed potential to support assistive technologies design that reflects children's need for self-determination and independent/autonomous action (Horn & Kang, 2012). As people learn the fabrication techniques, the objects and processes themselves become probes, enabling a shared understanding of design thinking that in turn leads to a greater ability on their part to advocate on behalf of particular needs/objects, and most importantly to see themselves as sources of ideas, insights and growing design expertise.

Help Children Help Others

During our second visit we discovered an iron workshop in a school, where students with mild cognitive disabilities learn arc welding and working scrap iron. They were repairing iron gates and building flower stands from discarded iron, which they sell locally. We had the chance to include several of these children in our study and obtained valuable feedback on the design and use of our devices. We see an opportunity for the Do-It-Yourself philosophy to be embraced for the design of our devices–and AT in general–in underserved communities in a way to include young individuals with mild cognitive disabilities in the fabrication process so that they build or assemble the physical parts of the device themselves. This shifts the focus from «design for disabled» to supporting them making things for each other. We plan to explore the possibility of these children being given the opportunity to learn soldering skills so that they may assemble and maintain assistive devices. This would include the attaching of switches at various locations on a user's wheelchair or bed frame so that the assistive devices could be used in accordance with a child's limited physical movements. As well, using their metalworking skills, the children could fabricate components to repair damaged assistive devices locally as well as custom mounts to attach communication devices to wheelchairs.

Conclusions

Designing assistive technologies tailored to the specific needs of children is especially challenging in resource-limited contexts such as orphanages and schools for disabled children in Cochabamba. We recognize the need for more in-depth analyses of disability design projects for marginalized people that would help increase the community awareness on the opportunities and challenges of these peculiar contexts. It is critical to build the foundations for a transdisciplinary dialog among researchers and practitioners of different areas such as computer science, interaction design, critical disability studies and early childhood studies that would benefit from cross-fertilizing interactions. The aim of our research project is to understand how to build capacity for design thinking that starts with the needs of the individual, developing into a community support network, and ultimately sharing and building capacity in other locations using social technologies. To this end, we established Diseñando para el Futuro as a fabrication hub and non-profit organization in Cochabamba. Our staff are working with members of the different sites we visited, teaching how to design and fabricate items for themselves and their community, raising stakeholders' ability and confidence to develop their own artifacts. We focus on supporting the design of devices and physical objects that will enable individuals to better communicate their needs, engage with their environment, and hopefully increase the level of autonomy and self-advocacy in their lives. Our fabrication lab has been recently established and we are learning about its role of serving the needs, wellbeing and empowerment of the local community and how our Bolivian experience can scale to other countries with different challenges. Our pilot project is presently being developed as a full long-term project.

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